DOCUMENT RESUME

ED 266 617 EC 182 035

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TITLE Childhood Cancer: A Medical, Psychosocial and Educational Approach.
PUB DATE Oct 85
NOTE 8p.; Paper presented at the Council for Exceptional Children/Division for Early Childhood National Early Childhood Conference on Children with Special Needs (Denver, CO, October 6-8, 1985).
PUB TYPE Speeches/Conference Papers (150) -- Guides - Non-Classroom Use (055)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS *Cancer; Coping; Early Childhood Education; Educational Needs; *Emotional Adjustment; Parent Role; *Parent School Relationship; *Psychological Needs; Special Health Problems; *Student Needs
IDENTIFIERS *Pediatric Cancer Patients

ABSTRACT

The paper examines the psychological and educational needs of children with cancer. The importance of cooperation among the home, hospital, and school is stressed. Potential effects of cancer and treatment include decreased school attention, drops in IQ scores, and diminished abilities of the central nervous system resulting in impaired perceptual motor, sensory, reasoning, and intellectual activities. Psychological effects, including depression, behavior problems, and unwillingness of parents to discipline the children are noted. Implications for teachers dealing with children who have cancer are considered. Indicators of potential problems, including close exposure to chicken pox, paleness in the face, and excessive bruising are listed. The paper concludes with a brief summary of ways in which the school can facilitate the pediatric cancer patient's reentry to school. (CL)

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Childhood Cancer: A Medical, Psychosocial and Educational Approach

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ED266617

Public Law 94-142 defines "other health impaired" as those with limited strength, vitality or alertness, due to chronic or acute health problems such as leukemia, hemophilia, or sickle cell anemia which adversely affects a child's educational performance. School districts have a wide range of existing services to meet the needs of health impaired students but the needs of the cancer child are basically unmet.

About 6,000 youngsters are newly diagnosed with cancer in the United States annually. Recent advances in children's oncology have been so pronounced that even conservative medical authorities call them "spectacular". The most common childhood cancer is acute lymphocytic leukemia (ALL), a disease of the blood-forming tissues. It is most prevalent in early childhood with a peak incidence at 3 to 4 years. Twenty years ago, almost every child with ALL died within a few months; today, about half the children stricken are able to hold a remission for 5 years, and of those who reach the 5-year mark, about 85% are expected to live a normal lifespan. The next most common forms of cancer in children, in order, are tumors of the central nervous system, including brain tumors; tumors of the lymph tissues, such as Hodgkin's disease and non-Hodgkin's lymphoma; neuroblastoma, a malignancy of the sympathetic nervous system (most tumors of this kind develop in the abdomen); Wilms's tumor, of the kidney; rhabdomyosarcoma, a muscle malignancy; and osteogenic sarcoma, a bone cancer. The chances of long term survival with these cancers depend on each child and the speediness of diagnosis, but in general, the rates range from about 85% survival for Hodgkin's disease and Wilms's tumor to 60% for bone cancer and 20% for brain tumors. More boys get cancer than girls; more white children than black, youngsters with certain chromosomal disorders - like mongolism or dwarfism - have an increased chance of getting cancer.

Modern medical advances and quality medical care now make it possible for children to live with cancer and to prepare for their future. Accordingly, the home, the hospital, and the school must work as a team in the total care of the child. Each has a unique contribution to make in order to maximize the child's potential to continue normal growth and development as he goes through the treatment process. Any weak link can jeopardize the efforts of the other members.

A child's development continues while he has cancer and may, in fact, be accelerated by the stress of the disease. This possible acceleration makes the child's environment during illness especially important. The environment must allow normal development during abnormal circumstances. In a young child, time is precious because developing children have short periods to master specific skills, loss of these opportunities may slow development.

As more amd more children are living with cancer, attention must be turned to the question of minimizing its effects on their development. The care of the child with cancer should be directed at producing a truly cured child; that is, one who is mentally healthy and who can function at an age-appropriate level in society. For this to be possible, treatment centers and schools must pay attention to the whole child; if we do not...we may find an artificially cured

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child who has not developed mentally, and who has not learned the experiences a normal child needs to learn to be competitive with his peers.

Children are resilient. By giving them opportunities to succeed in school, parents, health care professionals and teachers together help them better cope with what they are going through medically. By succeeding socially and academically, the children have an area in their life in which they can have some control; they are like the rest of the kids; they have a future and thus they can better tolerate the medical treatments and side effects.

The effects of treatment may be put in perspective by a closer look at the therapy process of ALL. In treating this type of leukemia, the child is hospitalized immediately and given treatment to induce remission. The time required for this varies, but he may be hospitalized for 1 to 4 weeks. After remission has been achieved, the child is released from the hospital and treated in the outpatient clinic for a few more weeks to consolidate the remission. Once that process has been completed, the child must return to the clinic regularly for treatment aimed at maintaining the remission. These treatments vary according to individual protocols but usually require the child to atttend the clinic either one day per week or one full week every 5 weeks. Maintenance therapy usually continues for 2-1/2 to 3 years. This means that the child misses 20% of the school year for 3 years at a minimum, if the chemotherapy causes nausea, etc., he may miss more. If there is a relapse, the process starts again, and intensive treatment is reinstituted in an effort to bring about another remission.

A study by Meadows (1984) showed that 11 of 18, or 63%, children with cancer demonstrated a decrement of 10 or more points in their full scale IQ scores between the initial test following remission and the test administered at least 3 years later. The children who showed the greatest decline were between 2 and 5 years at diagnosis. Se veral areas of neuropsychological functioning were especially noted to be affected by the treatment. In addition to general memory, this included visual-motor integration, psychomotor problem solving, memory for auditory sequencing, and abstract reasoning ability (Levine, 1984).

In some cases, a child's disease or its treatment can affect the central nervous system and reduce perceptual-motor, sensory, reasoning, and intellectual activities. In the case of brain tumors, such effects can be severe (Bamford, 1976; Morris, 1977). Recent studies of children receiving irradiation of the central nervous system also point to a possible negative effect on intellectual functioning (Eiser, 1978; Elliot, 1977; Pavlovsky, 1983). And a study of the effects of chemotherapy on the central nervous system indicates that it too may adversely affect intellectual functioning (Meadows & Evans, 1976; Robinson, et al, 1984).

Children, even very young ones, are astute and know when they are having difficulties learning. Unfortunately, the adults in the child's environment may attribute the learning difficulty to the child's emotional response to his illness.

The effects of cancer and particularly of the treatment may make a child look and feel different at a time when he or she has a strong need to conform. Chemotherapy or radiation treatments cause hair loss and noticable weight fluctuation, or the patient may lose a limb through amputation. Changes in

appearance, stamina, coordination, and sense of well-being require physical and emotional adjustment and threaten the child's developing self-image and ability to compete successfully with classmates.

Depressed and disheartened by the illness, some parents do not recognize their child's potential and have low expectations of his ability to achieve. Children sense this lack of faith in their future and respond to these messages with feelings of helplessness, discouragement, and sometimes rage.

Behavior problems arise in most chronically ill children. Parents are naturally sorry for the sick child and hate to deny him anything. Children soon learn to take advantage of this. A survey of parents found that 2/3 of the respondents thought they had discipline problems (Lawrence, 1978).

Parents may blame themselves for the child's illness, feeling they have, in some way, neglected him. In order to make up for this fancied neglect, they become over-conscientious and over-strict with the child. Over-protection interferes with the development of normal assertiveness and independence. It may result in dangerous rebellious behaviors, or passive dependency and excessive reliance on others. The child may be continuously angry at the unjust fate which singles him out as a victim of this disease. Not realizing what makes him angry, he may vent his hostile feeling on the most convenient object - often a bewildered and long-suffering parent. One parent summed it up, "A sick child can be very mean. It is no coincidence that the sign of Cancer is the crab." However heartless it may seem to scold a pale little kid with no hair, the parent must learn that it is more heartless to make it appear to him - as it will if he is over-indulged - that his parents have given up on him.

Although most parents approve of sending their child to school after remission, they may do so reluctantly. The child is now perceived as vulnerable; they fear he will not be protected at school and, without their constant surveillance, may once again become acutelly ill (Rose, 1982). This concern may be realistic, for at times there may be a risk of becoming infected by classmates. Whenever a child with cancer runs a fever, he must be hospitalized. For parents who believe the child will die soon, school may seem an unnecessary burden. Whatever the reason, the parent's reluctance to send the child to school often comes from their own feelings of guilt or fear of losing the child. In severe cases, the child's and parents' fears may combine to produce school phobia, characterized by a refusal to attend school, fear of separation from the mother, and somatic complaints.

School presents its own difficulties. Incredible as it may seem, many teachers isolate children because they are afraid that cancer is contagious. Sometimes they fear that the child will keel over and die in the class.

The teacher shares responsibility for the child's care, but a teacher is neither trained nor emotionally prepared to face serious illness in the classroom. It should be remembered that while health care professionals deal with children with cancer and chronic illness on an ongoing basis, teachers rarely come in contact with such students. Parents are the primary source of information for the teacher, with the medical center and local physicians supplying information less than 5% of the time.

The teacher also carries her own emotional baggage when it comes to dealing with cancer. She has some family member or close friend who was affected and chances are knows of several people who have died from cancer. When the doctor tells the parent that their child has a 60% chance of survival, they only "hear" a 40% chance of death. The parent then transmits this information to the school.

Teachers are parents too. Just as it is difficult for a parent to discipline a sick child, it is equally difficult for a teacher. Typically, a teacher will not only ease up on discipline but will not require the child to complete all of his assignments. Although the effects of chemotherapy and irradiation may affect the child's learning abilities, this is not the biggest problem he must overcome. The child maintains good grades during his treatment phase but later his grades begin to drop. While under treatment, the teacher does not require the child to complete assignments missed while at the clinic or in the hospital. She lowers her expectations of the child relative to his peers and inflates his grades. When the child is "cured" and off treatment he is suddenly forced to compete with his classmates but he is lacking the basic skills and cannot keep pace.

A large number of children with cancer are diagnosed under the age of five. Most parents choose not to send these youngsters to preschool and, therefore, when they start kindergarten or first grade they are often described by their teachers as "environmentally deprived". Due to the immaturity of their brains at the time of the initial diagnosis and treatment, these are also the children most susceptible to potential learning problems at the completion of treatment.

The pediatric cancer patients' successful re-entry into school is achieved when the family, school and treatment center work together. Medical information transmitted to the school must be child-specific and education related. Teachers and other personnel should be given information relating to cancer and the child's condition, including any limitations imposed by the disease or treatment; upcoming clinic visits, and possible reactions to treatment; side effects and possible complications of the protocol; and infectious diseases that would be dangerous to the child. The teacher should ask the parent for permission to contact the treatment team directly.

The parent or treatment team should be notified immediately if the school notices any of the following:

1. Temperature of 101 degrees Fahrenheit or above.

2. Close exposure to Chicken Pox as this can be life-threatening to a child receiving chemotherapy. (A special vaccine can be administered within 96 hours of exposure.

3. Excessive tiredness or inactivity.

4. Paleness in face, may be especially noted in the lips or inside of the lower eyelid.

5. Nosebleed that will not stop with pressure.

6. Excessive bruising.

All of the problems listed above may happen, but do not be waiting for them. They are only indicators of potential problems.

There are many ways in which the school can facilitate the patient/students reentry to school. To achieve as "normal" an experience as possible and aleviate the potential of school phobia, the child should attend the regular classroom as soon and whenever possible. Intermittent homebound or dual homebound staffing allows the child to be both in the classroom and to receive extra support for the time he is out. Arrange for the child to have a second set of books at home. When the child knows his clinic visitation schedule, assign him the necessary work to complete while he is out. This way when he returns to school he will be "in step" with his classmates and not always trying to play catch up. Hand pick an appropriate teacher. Because the disease and its treatment may have affected intellectual development, the child should be assessed continuously for any learning difficuties or behavioral problems.

It should also be remembered that siblings are also affected. They often must struggle with feelilngs of fear, anger, jealousy, concerns over their own health, or even guilt because they are healthy. They may also be the target of the cancer child's anger and frustration. These feelings can be translated into the classroom by behavioral changes, failure to hand in homework and assignments, withdrawal, or a drop in grades. At times they may miss school out of anxiety or a need to help at home. They should be able to share their concerns with a counselor and be assured that their feelings are normal.

The need for school intervention must be a dynamic, ongoing process. Teachers change annually. The medical status of the patient/student changes - some complete treatment, others relapse, and some develop residual problems which affect ac ademic performance even long after treatment stops. The classroom teacher cannot relate to the various drugs such as Prednisone, Vincristine or Adriamycin. However, by establishing good communication with the parents and the treatment teams, she can learn what the various side effects are and the implications for education. The importance of early success in school performance cannot be overemphasized. It provides the foundation for later academic and occupational success.

BIBLIOGRAPHY

Bamford, F.N., P. Morris Jones, D. Pearson, G.G. Ribeiro, S.M. Shalet, and G.G. Beardwell. "Residual Disabilities in Children Treated for Intracranial Space-occupying Lesions", Cancer, 37:1149-51, 1976.

Eisener, C. "Intellectual Abilities Among Survivors of Childhood Leukemia as a Function of CNS Inrradiation", Archives of Disease in Childhood, 53:391-95, 1978.

Elliott, Carolyn St. John. "Radiation: A Focused Assault", pp. 37-44, In: Helping Cancer Patients-Effectively. Horsham, PA: Intermed Communications, Inc., 1977.

Lawrence, Susan. "Results: Candlelighters Discipline Questionnaire", unpublished report presented to the Division of Cancer Control and Rehabilitation, Silver Spring, MD, April 12, 1978.

Levine-Pfefferbaum, B.D. Copeland, J. Fletcher, H. Ried, N. Jaffe, W. McKinnon. "Neuropsychologic Assessment of Long-Term Survivors of Childhood Leukemia", American Journal of Pediatric Hematology/Oncology, V6 N2, Summer, 1984.

Meadows, Anna. "Learning Problems Associated with Therapy for Acute Lymphocytic Leukemia (ALL)", The Candlelighters Foundations Progress Report, V4 N3, 1984.

------ and A.E. Evans. "Effects of Chemotherapy on the Central Nervous System: A Study of Parenteral Methotrexate in Long-Term Survivors of Leukemia and Lymphoma in Childhood", Cancer (Suppl) 37 (No.2): 1079-85, 1976.

Morris, J.P. "Side Effects of Treatment of Brain Tumors: Late Effects of Treatment", presented at the Ninth Annual Meeting of the International Society of Pediatric Oncology, Philadelphia, September, 1977.

Pavlovsky, S., J. Castano, R. Leiguardo, N. Fisman, N. Chamoles, R. Moreno, R. Arigaga. "Neuropsychologic Study in Patients with ALL", American Journal of Pediatric Hematology/Oncology, V5 N1, Spring, 1983.

Robison, L., M. Nesbit, H. Sathev, A. Meadows, J. Ortega, D. Hammond. "Factors Associated with IQ scores in Long-Term Survivors of Childhood Acute Lymphocytic Leukemia", American Journal of Pediatric Hematology/Oncology, V6 N2, Summer, 1984.

Paper presented at the Council for Exceptional Children/Division for Early Childhood National Early Childhood Conference on Children with Special Needs
Denver, CO, October, 6-8, 1985

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